

FORWARD

SPRING 2016

LIVING YOUR BEST LIFE WITH CANCER AND BEYOND

Life Without Pain

New approaches to managing chronic post-cancer pain

Health Care After Active Treatment

Improving post-cancer followup through communication

Accessing Disability Supports

A survey of aid opportunities for eligible cancer survivors

Sherry Dunn

How dragon boating, and the sisterhood aboard *Spirit Abreast*, helped this visual arts teacher recover from aggressive breast cancer



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Inspired Survivorship



Welcome to the Spring 2016 edition of *Forward* magazine. I am pleased to share this issue with you.

One of the reasons I chose to join the BC Cancer Agency was the leading-edge cancer research happening here. Today, there are more than 200,000 cancer survivors in British Columbia, and thanks to our talented researchers and physicians working across the province, that number will continue to grow in the coming years. So, it is important that we provide you – our survivors – with resources to assist and inspire you as you move forward.

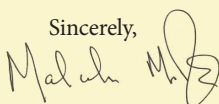
Inside this issue, you'll find articles with helpful tips on how to transition from oncology care to primary care, exercise recommendations, and information on the best way to access disability supports. You'll also find inspiration as we share two very special stories of survivorship.

Twins Jan and Lee Crawford, both cancer survivors, talk about switching between the roles of caregiver and patient, and how art was a powerful force in their healing process.

Our cover story explores Sherry Dunn's cancer journey. A breast cancer survivor, Sherry found hope and a sense of community when she joined the dragon boat team aboard *Spirit Abreast*, and credits the

exercise as an important non-medical part of her treatment.

I hope you enjoy this issue, and I encourage you to visit our website at www.bccancer.bc.ca to access information and resources to help you in your journey.

Sincerely,

Dr. Malcolm Moore
President
BC Cancer Agency



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Battle of the Bulge

Post-cancer weight gain poses risks for survivors, which is why it's so important to eat well to achieve a healthier weight

If you are carrying around extra weight following your cancer treatment, you're not alone.

"Weight gain is a common side-effect of cancer treatment, particularly for breast or prostate cancer patients," says Cheri Cosby, clinical co-ordinator and registered dietitian, Oncology Nutrition, BC Cancer Agency, Vancouver Island Centre.

"As we are seeing better cancer outcomes in the province, we have more survivors, and from them we are learning there is an increased trend in weight gain following treatment," says Cosby. It's a fact that is turning the notion that cancer patients mostly experience extreme weight loss on its head.

Research shows that extra body weight increases the risk of recurrence, along with additional primary and secondary cancers. The statistics are sobering: in separate studies of prostate and colorectal cancer patients, the increased risk of mortality for obese patients was 15 per cent.

"Extra weight also contributes to other diseases, including heart disease and diabetes," says Sandra Gentleman, registered dietitian, BC Cancer Agency, Vancouver Island Centre and Island Health. "Cancer treatment is saving people's lives, but if the weight gain side-effect causes quality-of-life or other health issues, that's a concern."

Given the overwhelming amount of information out there on the subject of weight loss, how do you make dietary choices that won't compromise your health or any ongoing treatment?

"First, be wary about taking advice from anyone who is selling a product," says Gentleman. "There is a ton of misinformation out there."

The best thing to do is to seek out a registered dietitian to get personalized advice. Gentleman also says support groups have been shown to help people lose weight more slowly – an important key to keeping the weight off: "Extreme dieting just adds to the problem."

Much of the problem of weight gain can be attributed to what is known as "The Western Diet," says Cosby. "We're talking about people who eat a lot of meat, a lot of fat and processed foods, and low amounts of foods with fibre, such as fruit, veggies and whole grains."

Making some simple changes to how you eat can make a big difference over time. ►



For a healthier diet that will help you lose weight:

1. Make smart protein choices: choose more poultry, fish, seafood, eggs, beans, lentils and low-fat dairy
2. Add more fibre to your diet: boost your veggies and fruit to a minimum of 2 ½ cups daily, and try adding 1/3 cup of nuts or 2 tablespoons of nut butters to your diet each day
3. Limit added animal and total fats: substitute these with 1 to 2 teaspoons of uncooked olive oil a day.



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The Skinny on Red Meat

You may have heard about the controversy last fall over processed meats and their link to an increased risk of developing cancer, also known as “Bacongate.” Dietitians confirm that in studies of large populations, research has consistently shown that people who eat more red meat (especially processed meats) have higher incidences of the three most common cancers (breast, prostate and colorectal).

The health risks arise from meat’s higher fat content, added chemicals and the tendency for big meat-eaters to eat less fibre, resulting in the meat spending too much time in the digestive system.

The recommendation: red meat (including pork) should be limited to no more than three servings a week, and processed meat to no more than one serving a week.

“Really, you should think of anything that is salted, cured or processed (e.g., bacon, sausage, pepperoni or ham) as ‘candy’ not as food,” says Gentleman. “You’re not eating it for health, but more as a treat, and these items should definitely not be a staple in your grocery cart.”

Where to Get Good Dietary Information and Help

Looking for some help regarding your diet?
Here are some excellent resources:

- Call 8-1-1 and ask for the Oncology Dietitian at HealthLinkBC
- BC Cancer Agency offers nutrition resources at regional centres
- Find a registered dietitian in your community for expert advice, including the right choices for complementary and alternative therapies, and/or nutritional supplements that will work with any medication you may be taking
- www.bccancer.bc.ca ■





Exercise Benefits Cancer Survivors

Whether you were an elite athlete or a couch potato before your cancer treatment, you will definitely benefit from exercise after treatment, says Kirstin Lane, PhD, instructor at Camosun College in the Centre for Sport and Exercise Education.

“The research shows a lower rate of cancer recurrence in those who are physically active after treatment,” says Lane. “Plus, activity releases the ‘feel good’ hormones – endorphins – that help boost general mood and outlook, and which are proven to play an important role in recovery.”

Moderate physical activity, such as a brisk walk or resistance training, is safe for most cancer survivors and, surprisingly, also the best way to beat fatigue! You can use the chart (right) to build an exercise program that meets your individual needs.

When to postpone physical activity

Check with your health-care provider if you have:

- 1 chest pain/discomfort or an irregular heart beat
- 2 dizziness, blurred vision or fainting
- 3 pain and swelling that limits your movement
- 4 a fever or are anemic

Where to get help

- 1 If you are new to exercise, or have complex needs as a result of your treatment or health history, Lane recommends getting advice from a Certified Exercise Physiologist (CSEP) to help set up a program that is safe and works for you.
- 2 Many community recreation centres have weight room attendants who can help you learn proper exercise technique.
- 3 Personal trainers, while more expensive, can also design a safe and individualized program for you.

| | Stronger Heart | Stronger muscles and bones | Fall prevention | Weight loss |
|----------------|--|---|---|---|
| FIRST STEPS | Start with 10 minutes at a time of continuous activity such as walking, 1-2 times/day, on most days of the week. It helps to choose activities you enjoy. | Start by using resistance bands or light weights, up to 15 reps at a time, 2 days/week; do exercises that target major muscle groups. Stronger muscles = more lean muscle mass | Start by standing with one foot in front of the other, eyes open; once you can do this for 30 seconds, try closing your eyes. Always have something secure nearby to hold on to in case you lose your balance. | To start, follow the advice under “stronger heart.” Consult a registered dietitian about dietary changes. Even a 10% weight loss can have a big impact on overall health. |
| NEXT STEPS | Work up to 30 minutes of continuous activity at least 5 days/week. This also helps beat fatigue! | Increase weight and/or resistance so muscles start to tire between 8-12 reps; do this 2 days/week | Try tandem walking (one foot directly in front of the other in a straight line), or walk on your toes or heels; try to do 10 minutes/day of balance exercises. | Try to get 150 minutes/week of moderate intensity cardio/aerobic activity. |
| MOVING FORWARD | Increase the intensity to “moderate” by doing the same exercises at a faster pace, adding hills or more resistance on a bike. | When doing 12 reps becomes easy, either increase weights or number of sets; work towards 3 sets of 8-12 reps on 2-3 days/week. | Increase to 20 minutes/day Try different surfaces, such as a pillow, balance board or Bosu ball to really challenge yourself. | Increase your cardio/aerobic activity to 240 minutes per week. |

For everyone:

A proper warm-up and cool down with stretching exercises after exercise are recommended. Start slowly and listen to your body. Sit less and move more throughout the day (stand up, stretch, and get a drink of water if you’ve been sitting for a long time). Don’t compare yourself to others – everyone has their own needs and limitations and recovers differently.

Definitions:

reps = the number of times to perform an exercise
sets = the number of times you repeat the exercise for the set number of repetitions (e.g., you may do three sets of 8-12 reps) ■



“Art and healing groups are about developing mind-body skills to help people cope.”

– Lee Crawford

Sister Survivors

How identical twins Lee and Jan Crawford found comfort and coping skills by expressing their cancer journeys through art

“It’s challenging to talk about something this life-altering,” admits cancer survivor Lee Crawford, a registered clinical counsellor and art therapist.

“Most people don’t have a language to express it,” adds her twin sister, Jan, a high-school art teacher and prolific artist.

Lacking words, the sisters turned to art.

Jan was a 28-year-old student at Emily Carr Institute of Art and Design when she was diagnosed with Hodgkin’s lymphoma in 1986. Overnight, she went from planning her future to facing her mortality. Her sister Lee became her caregiver, and supported Jan through chemotherapy treatments every three weeks for a year.

Understanding that creative expression would help Jan cope, Lee drew on art therapy skills from her own studies. “Draw yourself as a tree, how you feel,” she urged Jan.

“It [her first hand-drawn image] came right out from my gut,” Jan recalls. “The black in the background of the tree was the cancer, and that was how the series started.”

Jan went on to create 13 drawings during her treatment, using stitching, collage, coloured pencil and graphite.

Jan’s art provided her with “an element of positive control: purpose and meaning, grounding, something to concentrate on besides her next treatment,” says Lee.

Today Jan’s original drawings are displayed in the chemotherapy treatment area of the BC Cancer Agency’s Vancouver Centre where, according to staff, patients continue to relate to them as they face their own treatments.

Jan wrote a book featuring the drawings entitled *Art and Healing – An Artist’s Journey through Cancer*. Five of the drawings were included in a first-of-its-kind show in California of works by artists who survived cancer.

In the way of twins, Lee worried that what happened to her sister could happen to her, too.

In 1994, suffering severe neck pain, she insisted the doctor X-ray her chest as well as her

neck without knowing why. Doctors quickly discovered non-Hodgkin’s lymphoma in her lungs, a condition that required Lee to undergo chemotherapy from spring to fall that year.

“I felt dread, because I knew what to expect having walked Jan’s cancer journey with her,” says Lee. The sisters had switched roles.

Lee was still exhausted from those treatments when the cancer recurred a year later. With chemotherapy no longer a viable treatment option, her only chance for survival was a bone marrow transplant. The odds of finding a match were usually about one in 500,000, but Lee felt “instant hope and relief” on learning that having an identical twin greatly increased her chance of survival.

For three weeks prior to the transplant, Lee underwent daily radiation and received medications and chemotherapy to prepare her body to accept the marrow.

“There’s a fine line between treating you and killing you,” says Lee. “But after the transplant my energy increased each day and I knew I was going to be okay.”

There were 15 people in Lee’s chemotherapy room when staff inserted the IV drip of donated marrow, and Jan remembers that every one of them had tears in their eyes: “It was a very spiritual and meaningful moment.”

Both sisters are deeply grateful for the medical community that saved them, but also recognize that their journeys involved much more than physical treatments.

“Back then, there wasn’t the same attention paid to a patient’s mental and psychological well-being,” says Jan. “They were so focused on keeping people alive. I wish I could have had a therapist I could check in with regularly.”

“I continually had new issues – chronic worry, fear and fatigue – to say nothing of how isolated I felt among my friends.”

Today the field of psycho-social oncology validates the ongoing stress and emotional, spiritual, psychological and social issues that patients and survivors endure, in

addition to the physical and medical ones. And concerns don’t end when treatment does, says Lee: “Those issues can ebb and flow for the rest of your life.”

Lee was “psychologically and emotionally wiped out – just collapsed inside” during her second bout. She also faced additional issues. Unlike Jan’s cancer, non-Hodgkin’s lymphoma can cross tissue boundaries. Lee’s treatment resulted in infertility – another loss to grieve.

“But nobody said, ‘This is normal, here are the skills to handle it,’” says Lee. “People were beginning to survive cancer, and issues like stress, fear of recurrence, anxiety and depression were being recognized as part of recovery, but they hadn’t developed many resources beyond tips to ‘manage anxiety.’ I needed a weekly survivorship support group to validate my experiences and help me cope.”

Lee still uses art-making and mindfulness-based art therapy to cope with her survivorship experiences. Now a registered art therapist, she developed a counselling method for cancer survivors that’s part of her current practice.

For three years, the sisters have led Leukemia and Lymphoma Society art and healing groups for patients, survivors and caregivers. Lee also taught a Group Art Therapy for Cancer Survivors course as part of the masters in counselling program at Adler University. “Art and healing groups are about developing mind-body skills to help people cope and discover resources,” says Lee. “It’s like a form of creative meditation. When you’re calm, you see more choices for coping.”

The art and healing groups create community and weave together support, skills and hope. Jan and Lee know from experience that such support will help survivors thrive.

Jan and Lee welcome the opportunity to connect with other survivors. Contact them at www.jancrawford.com and www.leecrawford.com. For more resources and support, please contact the BC Cancer Agency. ■

Sherry Dunn

How dragon boating, and sisterhood of her team aboard *Spirit Abreast*, helped this visual arts teacher survive and thrive after aggressive breast cancer

“I defined myself as a survivor the day I was diagnosed,” says Sherry Dunn, now looking back to the day that coincided with her brother’s birthday, when she had confirmed what she already suspected: stage 3 invasive-aggressive breast cancer.

It’s an interesting term – survivor – and one that evokes a myriad of emotions among those diagnosed with cancer. For Sherry, then aged 42, the resolute belief that she would survive cancer, no matter what, was part of the positive attitude she knew she’d need to walk this path. Add to this the fact that she also had her mother by her side the whole way, together with a newfound passion for dragon boating, and Sherry says her hope stayed strong.

A visual arts teacher, Sherry, now 48, is reflective in a way that is fresh and authentic, and she passionately wants to help others, no matter the stage of their cancer experience.

Not surprisingly, the best word to describe Sherry’s cancer journey is the same word those who know her would use to describe her life: involved.

“I’d been healthy and active,” she recalls of the unexpected turn in her life. “Breast cancer wasn’t on my radar. My dad had had a stroke, my mother had a cancer diagnosis the year before when she was in her 60s, but I didn’t know about two other great aunts who’d had breast cancer. If I’d known, I might have been more on top of having regular mammograms after age 40.”

Her first response to the diagnosis was to begin learning everything she could about her illness, as well as the risk factors that could have led to this diagnosis when she was still relatively young. She focused first on her diet: “I didn’t feel in control of my cancer, but I could control what I put in my mouth.”

Sherry comes from a family of “committed carnivores,” but before she even started chemotherapy, she describes a “visceral aversion to a roast” served at a family meal. She decided that her body knew instinctively what was good for it; “what’s going to fight the cancer and what’s going to feed it.” In addition to giving up red meat, she gave up alcohol and processed meat, and began a low-glycemic-index eating plan that she still follows.

But it was just before she started chemotherapy that Sherry experienced the thing that would change her life more than anything else. A pink ceramic ribbon led to a chance conversation with Jo Houghton, who invited her to come out and watch a dragon boat regatta, and the team Jo had recently joined, *Spirit Abreast*. From that moment on, Sherry was hooked.

“I think going to that regatta was the best thing I did before chemo,” she says. “I saw what hope looked like; that people could still have fun, be involved with fitness, but also be emotional – share tears and laughter with others who understand it. I could imagine myself much more clearly on the other side.”





"I found a tribe," says Sherry Dunn (front), seen here with her sister survivors of the dragon boat team *Spirit Abreast*.



Sherry Dunn, a visual arts teacher, applied her talents to creating a new racing shirt design for her *Spirit Abreast* team.

surgeries, gone through Herceptin treatments and survived several complications with infections. Then I did hormone replacement therapy and landed on my ass.”

It was a rough time for Sherry, who woke up every two hours at night with severe hot flashes, even from a drugged sleep, and suffered from debilitating periods as a side-effect of Tamoxifen after her “chemopause (treatment-induced menopause)” was over.

Working with the various medical experts and the BC Cancer Agency Abbotsford Centre’s patient and family counselling program, Sherry’s medications were adjusted to deal with the side-effects of her cancer treatments. Her additional discovery of the side-effect known as “chemo brain” left Sherry extremely fatigued and challenged to continue at work – a situation she is still in the process of resolving along with occupational therapists from the BC Cancer Agency and the BC Teacher’s Federation.

But, back to the silver lining in all this – a concept many cancer survivors agree is real. For Sherry, her deep connection to the dragon boat movement, and – in particular – her *Spirit Abreast* team, has resulted in the meaningful intersection of better health through exercise, a powerful new sisterhood, and a community in which to give back through her art.

Her team captain, Jean, says she believes joining *Spirit Abreast* was the most important non-medical factor in Sherry’s treatment and recovery, and team mate Cathy Terpstra agrees: “By paddling with us, Sherry is more passionate about living her life to the fullest.”

Her experience is perhaps best embodied in a project she took on for the team this past year – a new racing shirt design that, much like a totem pole, tells the story of the *Spirit Abreast* team. Sherry worked tirelessly to pay tribute to now-passed team members whose hearts and souls are still present with every stroke.

“I found a tribe,” says Sherry, pointing out the power of the dragon boat movement to connect people all over the world. Sherry herself paddled with teams in Ontario and Alberta this past summer while travelling to visit family.

“We don’t always talk about cancer,” says Sherry. “We talk about everyday stuff, but we understand each other deeply when we meet up twice a week at Cultus Lake.

“My miracle cure was being part of an active community, believing I am the author of my own destiny, eating well and having a positive mental attitude.

“Our team motto is ‘keep smiling,’ and that’s something I sure do more of now.” ■

To learn more about Sherry’s team, *Spirit Abreast*, visit <http://www.spiritabreast.org/>

“I just kept finding women who shared my experiences. Not just women who had been through cancer, but those who shared the same treatment regime.”

Chemotherapy went as well as it could for Sherry, and through it all she worked and paddled as a new team member with *Spirit Abreast*. She was also able to see through two public art projects she had started with students, volunteers and community members.

Sherry continued to teach through chemotherapy, radiation and Herceptin treatments, followed eight months later by a full mastectomy.

“I had watched the cancer grow, but I wanted it gone,” says Sherry. “My mom said I was grinning ear to ear in my sleep when I came out of the mastectomy surgery because it was such a relief to have it out of my body.”

Sherry had taken the surgeon’s recommendation of a full mastectomy, and chose a concurrent reconstruction, as well as a reduction on the other breast.

Cancer being a journey for both halves of a couple, one wonders how Sherry’s husband, Bob Messer, a siding contractor, coped with the changes to his wife.

“My husband didn’t care if I had no breasts, or no hair; he just wanted me to be on the planet,” says Sherry reflectively.

“When you are first diagnosed, you don’t realize how much breast cancer is going to impact your relationship,” she says, adding that re-inhabiting her changed body was challenging. “I don’t have feeling in some parts of my body anymore. If someone touches me on the shoulder and parts of my arm, I don’t feel it. You ache in some of the places you used to play.”

While there had been a few complications along the way, overall Sherry was feeling good; working part-time and paddling, but not competing at regattas during chemo. However, she was in for a surprise: “I’d done the chemo. I’d done the radiation. I’d done the

Detecting Brain Cancer Risk

A new test may help save lives by identifying breast cancer patients at-risk for developing brain cancer

A team of international researchers, led by the BC Cancer Agency and the University of British Columbia, has developed a test that can predict whether women with breast cancer are at-risk for having the disease spread to the brain. The test could provide early detection of brain cancer and help save lives.

Women can live for years with breast cancer that has spread around the body, known as metastasis, but their survival rate is significantly diminished when it goes to the brain.

“My hope would be that this test becomes established and allows us to cure more women with cancers that go to the brain,” says Dr. Hagen Kennecke, an oncologist at the BC Cancer Agency and co-author of the study with Drs. Dave Voduc and Torsten Nielsen. “This study makes a strong argument that this is possible.”

The research, based on an analysis of about 4,000 breast cancer patients, found that testing for high activity in a particular gene product called AlphaBasic (α B)-crystallin could identify those women at increased risk of developing secondary brain tumours.

The study showed that only about 13 per cent of breast cancers tested positive for α B-crystallin. However, those women who did test positive were three times more likely to have the cancer spread to the brain. The α B-crystallin protein is common in the human body, but Kennecke says too much of it in breast cancer cells is a concern among cancer patients.

The risk of death was also higher among women who tested positive for α B-crystallin protein: a 36-per-cent risk of mortality within 10 years, compared to 25 per cent for those who tested negative.

“The study adds to our understanding that there are many different types of breast cancer and that they behave differently and affect patients in many types of ways,” says Kennecke. “It moves the field forward and makes α B-crystallin relevant to patient care.”

He says that the results have led to further analysis of the protein and gene, and whether they can be targeted to treat brain metastasis.



Dr. Hagen Kennecke,
oncologist at the
BC Cancer Agency

Kennecke hopes a test will be added to the regular cancer-diagnosis process to help detect the potential of breast cancer spreading to the brain: “Being able to figure out who is at-risk of developing what and being able to intervene earlier is key.” ■

The study was published in npj Breast Cancer, a journal affiliated with Nature, and included research from the Institute for Cancer Research (London, UK), the University of North Carolina at Chapel Hill and the University of Wisconsin-Madison. It was funded by the Breast Cancer Research Foundation, the U.S. National Cancer Institute, Cancer Research UK and the Canadian Breast Cancer Foundation.

Living with an Ostomy

Specialized nursing services and medical supports help address the concerns of cancer patients

When a cancer diagnosis includes surgery that leads to an ostomy (a surgically created opening in the abdominal wall for the removal of body waste), it's a life-changing experience for the patient, and for their family and support network.

"Most people go through the typical stages of grief (denial, anger, bargaining, depression and acceptance)," says John Christopherson, clinical counsellor, Patient and Family Counselling for the BC Cancer Agency.

Getting help adapting to both the practical and emotional challenges of living with an ostomy can be difficult, as hospitals have limited outpatient services for post-surgical needs.

Arden Townshend, RN, an enterostomal therapy (ET) nurse at the Ostomy Care and Supply Centre, says that about 2,000 ostomy surgeries are performed in BC each year, either permanent or temporary. The New Westminster clinic where she works was founded more than 30 years ago by Helen Manson, RN, ET; Helen's daughter Andrea (Andy) Manson, also an RN and ET, still runs the clinic.

"Helen realized that an ostomy is a lifelong thing, affecting people of all ages, and that your needs can change over time," says Townshend. "Nursing services at the clinic are free for patients who get their ostomy supplies at the on-site pharmacy, and run the gamut from learning to use an ostomy pouch, to wound care, to how to travel with a pouch."



Townshend says that the top three concerns for most ostomy patients are leakage, water (bathing and sports) and diet.

"It takes time to learn to trust the pouch system and be confident there won't be leaks or odour in public," says Townshend. "Once that's conquered, people can return to their normal activities."

Beyond the practical concerns are the emotional reactions to a surgery that changes the way your body works and looks. The impact can be similar to other body-changing surgeries, such as the loss of a breast, says Christopherson.

He says the key to supporting a family member or friend with an ostomy is to acknowledge their feelings and make it OK to talk about it.

"I try to meet them where they are, and sometimes just acknowledging that 'this sucks' goes a long way to helping someone feel understood. No one wants an ostomy, but I see people with them living good lives," he says.

"Sometimes when people are discharged from hospital they feel very isolated and abandoned," Townshend adds. "What I'd like everybody with an ostomy to know is that support is out there." ■

Helpful Resources:

For counselling related to any cancer, call the BC Cancer Agency's Patient and Family Counselling Service at 604-877-6000 ext 2194

The Ostomy Canada Association (ostomycanada.ca) has a branch in Vancouver and groups meet in other communities in BC.

Accessing Disability Supports

Jane Dyson of Disability Alliance BC, and **Maura Paget** from the BC Ministry of Social Development and Social Innovation provide answers to questions about financial and medical supports available to eligible cancer survivors through federal and provincial sources.

Q: *If I need financial or income support, what's available?*

A: Both the federal and provincial governments offer income support for people with disabilities, including people with a cancer diagnosis. The level of financial support depends on individual circumstances.

The federal government offers the Canada Pension Plan (CPP) Disability Benefit and the Employment Insurance (EI) Sickness Benefit.

The CPP Disability Benefit is a taxable monthly payment available to people who have contributed to the CPP and are unable to work because of a severe and prolonged disability. The average monthly amount is \$929, with exceptions under certain circumstances. To qualify, a patient must have contributed to the CPP through their job.

The EI Sickness Benefit is a twice-monthly payment available to people who cannot work

due to illness for a maximum of 15 weeks. For most people, the basic rate for EI benefits is 55 per cent of their average insurable earnings to a maximum of \$524 per week.

The BC Government also provides income assistance for people with disabilities through the Persons with Disabilities (PWD) designation. This disability assistance is for those who have a severe impairment as a result of a medical condition expected to last for at least two years into the future. The disability rate is \$906 per month for a single person with the PWD designation.

While there is no limit to the amount of assets a person can have to receive the CPP Disability Benefit, there is a ceiling of \$100,000 for individuals who have the PWD designation. Eligibility for the PWD designation is also subject to the person's income.

Q: *What about MSP, home care and other medical expenses?*

A: Those who are approved for PWD assistance have their Medical Services Plan (MSP) paid for by the provincial government and may be eligible for benefits such as medical supplies and equipment, medical-related transportation and nutritional supplements.

Home care is another option available. Patients should contact their regional health authority for information about eligibility requirements. Our experts recommend patients connect with a hospital social worker before surgery or treatment, which will help to ensure care is available when they leave. ■



The BC Cancer Agency offers online videos and handouts that explain how to access financial assistance. Information is available at <http://www.bccancer.bc.ca/health-info/coping-with-cancer/practical-support/financial-assistance>.



Life Without Pain

A new approach to chronic post-cancer pain management is having a profound impact on cancer survivors' quality of life



Dr. Pippa Hawley,
head of Pain & Symptom
Management/Palliative Care
at the BC Cancer Agency

While your cancer treatment is an increasingly distant memory, your pain still lingers. Perhaps your sense of touch feels strangely different when you run your hands over your cat's fur, or when you walk barefoot in the sand. You might be suffering from peripheral neuropathy, a condition many cancer patients experience during chemotherapy, but that can continue long after treatment ends. Trish Keating knows this feeling, and how it is to live with chronic pain first-hand.

Diagnosed with colon cancer almost six years ago, this Vancouver-based costume designer to the stars has had a rough ride. Her cancer metastasized several times, requiring numerous major surgeries and repeated rounds of chemotherapy and radiation. All this has resulted in both chronic pain related to the removal of a tumour from her spine, as well as what she describes as a "deadness" of feeling between her toes and the floor that dates back to her first round of chemotherapy.

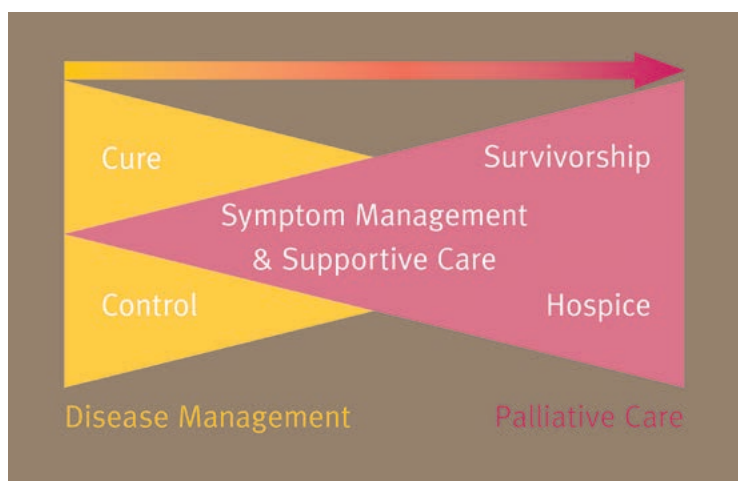
Luckily, Trish has someone who understands her pain in Dr. Pippa Hawley, head of the BC Cancer Agency's Pain & Symptom Management/Palliative Care program.

As someone who rarely experienced pain before cancer, and who credits her daily exercise regime with helping her manage now, Trish understands the reluctance of some cancer survivors to medicate what they consider low-grade, chronic pain. However, both she and Hawley point out the important advantages of having a sustainable pain management plan.

"None of us who've been through cancer want to dull our senses or feel less alive," says Trish, and it's here where an interesting concept comes into play.

While Hawley and her team at the BC Cancer Agency see only those cancer survivors in the greatest discomfort, they practise an approach that is about quality of life and pain management, no matter the outcome. The term used to describe this process is one they are working to

After studying HIV/AIDS patients early in her career, the UK-born and educated Dr. Pippa Hawley searched for new ways to describe the continuum of care faced by those diagnosed with a critical illness, where one possibility is the end of life, but where recovery and survivorship is also possible. Her "Bowtie Model" (below) redefines the term palliative care by showing how pain and symptom management are key to quality of life.
[http://www.virtualhospice.ca/HtmlAssets/images/Hawley%20fig%204\(2\).png](http://www.virtualhospice.ca/HtmlAssets/images/Hawley%20fig%204(2).png)



Pain Assessment Checklist

First-time visitors to the BC Cancer Agency's Pain & Symptom Management and Palliative Care program are taken through an assessment based on an alphabet mnemonic: "O-P-Q-R-S-T-U-V."

- **Onset:** When did the pain start?
- **Places:** Where does it hurt?
- **Quality:** Is it cold, hot, tingling, sore?
- **Relief:** What helps, or makes it worse?
- **Severity:** On a scale of 0-10
- **Timing:** When does it hurt?
- **Understanding:** What do you think is the cause of your pain?
- **Values:** What do you hope to achieve with pain management?

redefine: palliative care.

"I want cancer patients and survivors to feel comfortable seeking early, integrated palliative care," says Hawley, who urges even long-term survivors to talk to their family doctor if chronic pain is a lingering issue.

"The idea that you should be able to manage pain through brain power is potentially damaging in the long term," she adds, pointing out that it's too easy to feel like you have failed if the pain persists. She also sounds the alarm about taking largely ineffective over-the-counter pain medications such as acetaminophen (Tylenol®) and ibuprofen (Advil®), both of which can have serious side-effects, especially with long-term use.

"Specialists have access to classes of drugs such as gabapentin and the tricyclics – even methadone – that are far more effective and safer for chronic pain," says Hawley.

"It's interesting how you learn to live with things," observes Trish, who offers this advice to other cancer survivors experiencing lingering pain.

"Don't try to be brave. Pain directly affects your relationships with others, and those are what are keeping most of us going." ■

Health Care After Active Treatment

The key to effective post-cancer-treatment followup care lies in establishing good communication and understanding between you, your doctor and your oncologist

Thanks to the incredible advances in cancer treatment, there are more cancer survivors today than ever before. In BC alone, there are approximately 200,000 cancer survivors, and that number is expected to climb to 250,000 by 2030.

While it is important to ensure that cancer care and research continue to advance, it is also important to have clearly communicated post-treatment followup and monitoring plans in place for patients and their family doctors once active treatment is finished.

Transitioning can be tough

The first sore throat or unusual pain you feel after finishing cancer treatment might make you wonder if you should see your family doctor, or call your oncologist, to see if your symptoms are the result of your cancer treatment or the cancer returning. For most people, their family doctor is the first point of contact after treatment ends; they are the ones cancer survivors turn to first to meet their health-care needs and provide ongoing evaluation and monitoring.

Dr. Rob Olson, radiation oncologist at the BC Cancer Agency Centre for the North, says it is common for patients to feel somewhat lost when treatment ends.

“Leaving the safety net of regular treatment and monitoring can be daunting,”



Radiation oncologist Dr. Rob Olson says oncologists at the BC Cancer Agency are available to answer patients' post-treatment questions and concerns.

says Olson. “However, even when treatment ends, oncologists at the Agency are available to answer questions and address concerns related to a person's cancer care.

“Those should be shared with your family doctor too,” he adds. “Communication between your family doctor and oncologist is important.”

In addition, Dr. Cathy Clelland, head of Family Practice at Royal Columbian Hospital says, “Hopefully people are still seeing their family doctor for other health-care needs even while they are undergoing cancer

How to Feel in Control of Your Health After Cancer Treatment Ends

- Ask your oncologist to send a treatment summary to your family doctor and discuss it with your family doctor.
- Make sure you understand what monitoring needs to be done, how often it should happen and who will do it.
- Understand what medications you need, any potential side-effects and possible interactions with other medications or food.
- Have the phone numbers for your oncologist and family doctor handy, so you can call with any concerns or questions.
- Share important information about your post-treatment care with a family member or friend, so they can help you when you need it.

treatment. This ensures their family doctor has an understanding of what they are going through so post-treatment care can be effectively managed. If that hasn't been the case, they should see their family doctor after treatment ends to discuss what they have experienced and re-establish a relationship.”



Opening the lines of communication

Many oncologists provide comprehensive information to assist family physicians in their followup with patients, but there isn't currently a minimum standard in BC, so the level of communication between oncologists and family doctors can vary.

"Ensuring the post-treatment needs of patients are met in the community while optimizing the cancer care system's capacity to address the care needs of those in active treatment will require a shift in both culture and practice for both specialty and primary care," explains Karen Blain, Provincial Director, Survivorship & Primary Care Program, BC Cancer Agency.

Creating a Survivor Care Plan

Ensuring that the right professionals are providing care for each stage of the cancer journey is important.

"Family physicians can provide very effective followup care for people in their own community," says Clelland. "With a clearly identified post-treatment plan, we can ensure that proper monitoring takes place, enabling oncologists to focus on their patients undergoing active treatment."

Olson agrees: "There is ample evidence that shows managing followup care in the community is best for patients with most types of cancer. However, some types require more specialized followup, and that's why having clearly identified roles is important to ensure this happens appropriately."

In an ideal situation, patients should leave treatment with confidence that there is a clear understanding between their oncologist, family doctor and themselves about followup care and monitoring and who is responsible for it. A survivor care plan explains in detail the treatment

a person has had, what the potential side-effects might be, any medications that are currently prescribed, and recommendations for future screening.

Easing the way

You should feel comfortable asking your oncologist about a care plan as well. An emerging body of research indicates that written survivor care plans help increase the level to which family doctors talk to their patients about post-treatment care, and it also helps people feel more in control of their situation.

BC Cancer Agency's Karen Blain emphasizes, "We all care about our patients. The post-treatment journey is very important to health-care providers, just as the treatment journey is, and we want to work with our patients to ensure that post-treatment care is communicated and carried out appropriately and effectively." ■

Fundraising To Save Lives

Cancer survivor Diane Gagne Pacey participates in the Workout to Conquer Cancer to help support the cancer research that saved her life

Diane Gagne Pacey (left) is seen here with her husband Rob (centre) and a fellow member of team Pink Lemonade.



**BC CANCER
FOUNDATION**
partners in discovery

**WORKOUT
TO CONQUER
CANCER**

A fun fitness challenge

Diane Gagne Pacey says she was incredibly lucky to hear the phrase no one wants to hear: “You have cancer.”

She had her first mammogram in 2009, at which time a non-cancerous lump was found that needed to be removed. Then, a followup ultrasound the next year uncovered some abnormalities resulting in a whirlwind of tests. With the results came devastating news: Diane had breast cancer.

Unusual stroke of luck

“Lucky” is usually not the first adjective that comes to mind with a cancer diagnosis, but although it was an unnerving experience, Diane says she was fortunate for many reasons.

First, she says, she was in the hands of “the best medical professionals in the world” at the BC Cancer Agency, including her oncologist, Dr. Karen Gelmon: “They helped me get through a frightening ordeal, and Dr. Gelmon inspired tremendous hope in me.”

Gelmon presented Diane’s case to colleagues to discuss treatment options and results, which Diane says lifted her spirits – seeing all the nurses, technicians and doctors working together to find the best solutions for her.

“It made me feel like a whole team of people was caring for me and striving to do their absolute best for me,” she says. “After the first few meetings with them, I started to gain confidence that my story would have a happy conclusion – that things would get better.”

Diane also considers herself lucky that her breast cancer was caught sooner rather than later. She was diagnosed at stage 2, but was considered incredibly close to being diagnosed at stage 3.

“If it had been discovered even two months later, my story would have been very different,” she says. “I know there are too many people who aren’t as fortunate.”

Inspired to give back

Diane’s family and friends were by her side during her entire treatment and recovery, including her husband Robert and their dog, Luna. In fact, it was her extensive support network, and the level of care she received at the BC Cancer Agency, that made Diane feel extremely fortunate, and inspired her to want to give back.

“Through the whole cancer process I got to see first-hand how research and care really wrap around the entire journey. That’s what impressed me, to the

point where I knew I needed to do something to show my support,” she says. “I was so grateful to the BC Cancer Agency for the incredible care I received, I wanted to do whatever I could to give back.”

Seeing an ad for the BC Cancer Foundation’s Workout to Conquer Cancer event sparked her interest. The daylong fitness challenge was a way for her to fundraise in support of cancer research and take part in fun fitness activities she wouldn’t have been able to participate in while she was undergoing treatment.

Diane and her friends formed a team, Pink Lemonade. Together, they are fundraising and taking part in Workout to Conquer Cancer again this April.

“Workout to Conquer Cancer is like a celebration where you can say ‘I am here! I can do this!’,” Diane says. “Everyone has the hugest smiles on their faces the whole time.”

While she enjoys taking part in the event itself, Diane is quick to emphasize the importance of fundraising for events like Workout to Conquer Cancer.

“The BC Cancer Agency was so much a part of my life. Without them and the care they provide, I wouldn’t be here today,” she says. “Fundraising is the best way I know to help put the best tools into the hands of the brilliant and talented researchers there, and to support incredibly compassionate and dedicated clinicians, like Dr. Gelmon.”

Diane hopes her dedication inspires others to give back and help fuel the latest breakthroughs in cancer research.

“I want others to feel just as motivated as I do, to make sure researchers, right here in BC, can continue leading the world in cancer treatment innovations,” she says. “Fundraising leads to making new discoveries quicker than ever, saving as many lives as possible.” ■

The BC Cancer Foundation is the direct fundraising partner of the BC Cancer Agency. To learn more about the research initiatives we support, visit bccancerfoundation.com and join us online [@bccancer](https://twitter.com/bccancer).

Workout to Conquer Cancer

takes place April 2, 2016. To learn more, or to register for this fun fitness challenge, visit workouttoconquercancer.ca.



FOR A CURRENT LISTING OF EVENTS...

go to www.bccancer.bc.ca and scroll down to Upcoming Events.

Vancouver Prostate Centre's Supportive Care Program

Information Sessions 2016

DATE: March 16, 2016 – Nutrition Advice for Prostate Cancer Patients;

April 20, 2016 – Exercise for Prostate Cancer Patients

TIME: 6 pm

LOCATION: BC Cancer Research Centre, Gordon & Leslie Diamond Lecture Theatre (675 West 10th Avenue, Vancouver)

REGISTRATION: To register for these or future information sessions, please call Monita Sundar, PCSC program co-ordinator at 604-875-4485 or email PCSC@vch.ca



Survivorship & Primary Care Forum

This forum is for health professionals, researchers, patients and survivors.

DATE: June 8, 2016

TIME: 8:30 am – 3:30 pm

LOCATION: BC Cancer Research Centre, Gordon & Leslie Diamond Lecture Theatre, (675 West 10th Avenue, Vancouver)

DESCRIPTION: This forum will feature presentations focused on supporting and empowering survivors to live their best lives with cancer and beyond.

COST: Free

REGISTRATION: Seating is limited.

Register in advance online at

<http://surveys.phsa.ca/s/2016survivorshipforum/>

FOR MORE INFORMATION: Call 604-877-6000 ext 674619 or email to survivorship@bccancer.bc.ca

Relaxation Support Programs

Relaxation support programs are available at all BC Cancer Agency Centres.

DATE: Fourth Thursday of each month

FOR MORE INFORMATION OR TO REGISTER:

Contact the centre nearest you:

Abbotsford Cancer Centre: 604-851-4733;

Centre for the North: 250-645-7330;

Sindi Ahluwalia Hawkins Centre for the

Southern Interior: 250-712-3963;

Fraser Valley Centre: 604-930-4000;

Vancouver Centre: 604-877-6000 ext 672194;

Vancouver Island Centre: 250-519-5525



2016 Workout to Conquer Cancer

DATE: April 2, 2016

LOCATION: Richmond Olympic Oval, Richmond, BC

DESCRIPTION: Get ready to lunge, stretch and sweat towards a world free from cancer! Join in the fun of this full day of fitness fun sessions to raise funds for breakthrough cancer research.

REGISTER: As an individual or as a team at www.workouttoconquercancer.ca

FOR MORE INFORMATION: Call 604-877-6040 or

1-888-906-2873, or

e-mail us at workout@bccancer.bc.ca

**WORKOUT
TO CONQUER
CANCER**

2016 Ride to Conquer Cancer

DATE: August 27-28, 2016

LOCATION: Vancouver start

DESCRIPTION: The Ride to Conquer Cancer, presented by Silver Wheaton benefiting the BC Cancer Foundation, is a unique two-day cycling event that will take place on August 27 and 28, 2016. During this bold cycling journey, you will ride for two days through picturesque scenery from Vancouver to Seattle. Our vision is clear – A World Free From Cancer.

FOR MORE INFORMATION OR TO REGISTER: Visit www.conquercancer.ca or call 1-888-771-BIKE (2453)

New Normal Program

Cancer patients are often surprised to discover that the end of active cancer treatment is not the end of their journey. Instead, many survivors find themselves facing a host of new and unexpected challenges and concerns. To help them, the Canadian Cancer Society has launched a new pilot program called New Normal. “New Normal is a telephone-based peer-support program that connects trained volunteers who have been through cancer with people who have recently finished treatment and are experiencing challenges or have concerns about life after treatment,” explains Marie Dubord, manager of CancerConnection and New Normal. As survivors themselves, New Normal’s specially trained volunteers are uniquely qualified to validate and normalize what their survivor clients are feeling. They’re also able to guide survivors to the many programs and resources available through both the Canadian Cancer Society and the BC Cancer Agency on topics ranging from emotional and practical support to health and wellness. “Our volunteers are trained to connect patients to the kind of help they are looking for, either online, over the phone, at a Cancer Centre or in their community.”

To access the New Normal program please contact:

Direct: 604-675-7148

Toll Free: 1-800-822-8664

Email: newnormal@bc.cancer.ca

MyHealthConnect – Oncology

(www.myhealthconnect.ca)

Many people, once they’ve completed active cancer treatment, are eager to take back control of their lives and find ways to



Not sure where to begin after treatment for breast or colorectal cancer?

MyHealthConnect-Oncology is a free online goal-setting tool. It can help you set and track goals about the things most important to you after cancer. Get started today.

To get set up for an account or for more information, contact us at:

Toll-free: 1-855-444-1265 ext. 2
oncology@myhealthconnect.ca

www.myhealthconnect.ca

be the healthiest they can be. To help survivors achieve this goal, the BC Cancer Agency has partnered with the BC Alliance on Telehealth Policy and Research, led by Dr. Scott Lear, on a new web-based patient empowerment tool called MyHealthConnect – Oncology. “MyHealthConnect – Oncology is an online goal-setting tool that people can use to manage their health and wellness and track their personal progress after cancer,” says Jennifer Law, project manager with the BC Cancer Agency. This unique, easy-to-use website helps people set SMART (Specific, Measurable, Attainable, Rewarding and Timely) goals and then track their progress in five key areas of interest and concern to cancer survivors: managing fatigue, stress/emotion, social support, nutrition and physical activity. The site also features guidance, suggestions, tools and information on each topic area. Participation in the MyHealthConnect – Oncology pilot project is currently open to breast or colorectal cancer survivors, with a vision

to expand the service to all cancer survivors in the future.

To access MyHealthConnect – Oncology you need to register.

Please call the administrator at 1-855-444-1265 ext 2, or email oncology@myhealthconnect.ca for more information.

Note: The New Normal and MyHealthConnect – Oncology programs are funded by the Canadian Partnership Against Cancer.

Survivorship Nurse Practitioners

If you have had a cancer diagnosis, it’s vital that you receive ongoing followup care from a qualified medical professional. If you don’t have a regular family doctor, consider seeing a BC Cancer Agency nurse practitioner. Nurse practitioners are registered nurses with advanced clinical training. They diagnose and treat illnesses, order diagnostic tests (e.g., CT, lab tests, X-rays), prescribe (most) medications, consult with cancer specialists regarding your health care, monitor short- and long-term effects of cancer and treatment, refer you to specialist doctors, and screen for recurrence or second cancers. The program is accepting new patients who have a cancer diagnosis and do not have a regular doctor or primary care provider and who live in: Vancouver, Burnaby, Richmond, North Vancouver, West Vancouver, Surrey/White Rock, Langley, Delta/Ladner, Mission, Coquitlam, Port Coquitlam or Port Moody.

You do not need a referral from an oncologist to see a nurse practitioner.

Call the clinic nearest you directly.

Vancouver clinic: 604-829-2570

Fraser Valley clinic: 604-953-9706

Web: www.bccancer.bc.ca/our-services/services/primary-care ■

BE EPIC



Why do we ride?

We ride for our loved ones, we ride for ourselves. We ride because every moment makes an epic impact on cancer research and care across British Columbia. Take on your most meaningful challenge: The Ride to Conquer Cancer Presented by Silver Wheaton benefiting BC Cancer Foundation.



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